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13. ABSTRACT <i>(Maximum 200)</i> The objective of this study is to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. Participants were paired with a trained breast cancer survivor who provided them with ongoing peer support, in addition to specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Study volunteers received the standard Reach to Recovery training, in addition to a two-day skills training which prepared them to become breast cancer peer support volunteers and advocates. The fourth year of this study was devoted to collection, processing and preliminary analysis of 3- and 12-month data. In addition we developed and administered a volunteer survey; continued volunteer support and supervision; and edited the volunteer training manual. We have obtained a no cost extension in order to finish collection of the 12-month follow-up questionnaires, complete the analysis on the entire sample and write up the results for the final report and for publication.						
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Ann P. SIK July 29
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Annual Report

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Introduction

This report summarizes activities for the fourth year of our study to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. This randomized controlled trial asks four research questions:

1. Does this expanded program improve (a) quality of life with breast cancer; (b) participation with treatment decisions; and (c) satisfaction with care?
2. How do patient sociodemographic characteristics influence these outcomes?
3. What are the main benefits of this program?
4. Does participation in treatment decisions improve quality of life?

Women recruited into the study in five Kaiser Permanente medical centers were randomly assigned to the intervention or control group. Participants in the intervention group were paired with a trained breast cancer survivor (peer support volunteer or "peer supporter") who provided them, beginning at diagnosis, with ongoing peer support along with specific information and skills to help navigate the Kaiser Permanente Medical Care Program. Participants in the control group received the usual support services offered to women newly diagnosed with breast cancer, which in most cases included a referral to Reach to Recovery.

Body

Year Four Activities

The fourth year has been devoted to the collection, processing and preliminary analysis of three- and twelve-month participant data. In addition we developed and administered a volunteer survey. While not originally part of the evaluation plan, the collection of data from project volunteers will allow us to better understand the patient-volunteer matching process and to investigate the potentially beneficial effects of participation in a breast cancer peer support program on the breast cancer survivors (i.e. peer support volunteers) as well as the newly diagnosed women.

Volunteer support and supervision continued through the fourth year. This has included monthly volunteer meetings at all five facilities through December 1997 and telephone support as needed. As noted in previous annual reports, one of the primary tasks of this project has been the training supervision and support of a large and diverse group of women. The sixty-nine volunteers have varied in every possible way. They differed across educational, ethnic, religious and political lines and contact with women has continued to be tailored towards recognition of their individual and group differences.

In addition to regular volunteer support, we organized three special events to thank the volunteers for their work and to mark the end of the project's recruitment phase. These events

provided the opportunity for volunteers to express their feelings about ending work that for many had proved emotionally meaningful.

The fourth year has also included editing our volunteer training manual so that it can be used by others who are interested in developing similar peer support programs. Completion of this process and the editing of the trainer's guide and leader's guide will occur in the upcoming months. After study recruitment ended, we hoped that facility staff who had participated in the research would be able to incorporate the activities of the peer support program into their ongoing job description. Happily, one of the five facilities will continue to offer peer support to newly diagnosed women. In preparation for this ongoing commitment to the peer support program, the breast care coordinator (peer support program facility coordinator) at this site held a volunteer training this winter, in collaboration with the breast care coordinator at another community hospital and the American Cancer Society, using the project's volunteer training manual. Currently, this breast care coordinator supervises (and holds monthly meetings with) a group of peer support volunteers who are both newly trained and who were originally trained as part of our study. In this facility the breast cancer peer support program that was developed as part of this research project is being offered to newly diagnosed breast cancer patients as part of usual care. Unfortunately, the four other sites involved in this research project have not been able to continue the program after the research funding ended. While many of our volunteers in these facilities have expressed the desire to continue their work, the maintenance of such a service requires time and resources. Two facility coordinators have described to us their frustration and disappointment that they have been unable to continue this work on their own.

Below we summarize our evaluation methods and some preliminary results for the baseline and three-month surveys.

Evaluation Methods

The data for this study were collected using three self-administered surveys, completed at entry into the study (baseline), three months, and twelve months after entry into the study (see Appendix for copies of the surveys). The eligibility criteria for the study included women who had: (1) a first diagnosis of ductal carcinoma in situ or any stage invasive breast cancer; and (2) a study contact prior to primary treatment. Every week, during the recruitment period, study coordinators at each facility identified potentially eligible women from the pathology reports and obtained permission to contact these women from their surgeons. If the surgeon approved, the patient was sent an invitation letter (signed by her surgeon) along with a baseline questionnaire and an informed consent form. Upon receipt of these materials, each woman was randomly assigned to either the intervention or the control group. Three months later, she was mailed a three-month follow-up survey. If the survey was not returned within one week, the woman was sent a reminder postcard. If the survey was not returned after an additional week, the woman was sent a second copy of the survey. Finally, if the survey was still not returned after an additional two weeks, a research assistant spoke with the woman by phone and offered special assistance. This process was repeated with the twelve-month follow-up surveys.

In order to determine whether study enrollment varied by sociodemographic and disease characteristics of the participants, we linked the names of the women who were sent invitation letters to the data in Kaiser Permanente's cancer registry. Using a Chi-square test of association, we investigated whether participation in the study differed by age at diagnosis, race/ethnicity, marital status, stage at diagnosis, and treatment facility within Kaiser Permanente.

Next we determined whether the randomization to the intervention or the control groups resulted in samples with equivalent sociodemographic and disease characteristics. With data from the baseline survey, we used Chi-square tests of association to compare the groups on various characteristics (treatment facility within Kaiser Permanente, age at intervention, stage at diagnosis, race/ethnicity, education level, marital status, employment status, language, living situation, and social support).

We performed an intent-to-treat analysis to determine the effect of the intervention on quality of life at the three-month point. We compared the scores on the Functional Assessment of Cancer Therapy Scales (F.A.C.T.); the physical and mental components of the SF-12 Health Survey; the Center for Epidemiologic Studies Depression Scale (CES-D); and the Illness Intrusiveness Scale for the intervention and the control groups, using t-tests. In order to control for other sources of support and actual participation in the program, we conducted a sub-group analysis comparing the effect of the intervention among four groups of participants. The four groups were those who utilized (1) peer support only; (2) peer support and group support; (3) group support only; and (4) none of the above support resources.

Because we found that the intervention and control group differed on one baseline characteristic (the percentage of women who lived alone) we investigated, using t-tests, whether this variable affected any of the quality of life measures. We also tested to see if this variable interacted with the effect of the intervention on quality of life, using a multivariate analysis of variance model.

Preliminary Results

Overall, 37.8% (n=290) of the women who were sent the invitational packet returned the baseline materials and were randomized into either the intervention or control group (Table 1). The response rate varied by four factors: (1) age at diagnosis, with the older women being less likely to participate than younger women (Table 2); (2) race/ethnicity, with Asian/Pacific Islander, Hispanic, and other/unknown women being less likely to participate than African American and White, Non-Hispanic women (Table 3); (3) marital status, with married and widowed women being less likely to participate than single, divorced and separated women (Table 4); and (4) Kaiser Permanente facility, with some facilities recruiting fewer participants than others (Table 5). Participation did not vary by stage at diagnosis (Table 6).

The response rate for both the three-month and the twelve-month surveys were high. Overall 93.1% of the women enrolled in the study returned the three-month survey. 86.9% returned the twelve-month survey, with an additional 4.1% still pending, which ultimately could

bring the response rate up to 91%. Women in the intervention group were more likely to return both the three-month and the twelve month surveys than women in the control group (Tables 7,8).

The control and the intervention groups did not vary by any of the sociodemographic or disease characteristics that were measured at baseline with the exception of living situation. More of the women in the treatment group than the control group lived alone (31.5% vs. 15.6%, respectively) (Tables 9-18). Upon further analysis, we found that this variable did not affect any of the outcome scales that were measured on the three month survey and that it did not interact with the effect of the intervention.

At three months, there were no significant effects of the intervention on quality of life as measured by the Functional Assessment of Cancer Therapy Scales (F.A.C.T.), the physical component of the SF-12 Health Survey, the Center for Epidemiologic Studies Depression Scale (CES-D), or the Illness Intrusiveness Scale (Table 19). The only significant difference between the two groups was for the mental component of the SF-12 Health Survey, where the control group scored more favorably than the intervention group (Table 19).

In the subgroup analysis, stratifying by use of peer support and support group resources, we found that, among the women who had a peer support volunteer only, the women in the intervention group scored higher than the women in the control group on the overall F.A.C.T. scale, and the Physical Well-Being and the Functional Well-Being components of the F.A.C.T. scale (Table 20). There were no other differences in the effect of the intervention in any of the other subgroups (Tables 21-24). We also found that the differences between the intervention group and the control group on the mental component on the SF-12 Health Survey were no longer significant when stratifying by peer support and support group resources.

Conclusions

We obtained a no cost extension until July 1999 to complete the data analyses, write the final report and manuscripts. Planned analyses include (1) continued analysis of the three-month data; (2) analysis of the twelve-month data; (3) additional subgroup analyses to specify which subsets of patients get most benefit from the program; (4) analysis of the volunteer survey, alone to determine the benefit of participating in the program to the volunteers, and linked to participant data, to better understand the characteristics of a good volunteer-participant match. In addition we will finish editing the volunteer training manual, leader's guide and volunteer coordinator's guide.

Table 1: Overall Response Rates

Sent Invitation Letter	768
Enrolled in Study (N)	290
Enrolled in Study (%)	37.8%

Table 2: Response Rate by Age at Diagnosis

Age	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Under 40 years	22	9	40.9
40-49 years	150	70	46.7
50-59 years	233	103	44.2
60-69 years	198	67	33.8
70-79 years	132	30	22.7
80 plus years	21	6	28.6

Chi-square (5)=24.0, p<.001

Table 3: Response Rate by Race/Ethnicity

Race/Ethnicity	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
White, Non Hispanic	580	233	40.2
Black, Non Hispanic	63	24	38.1
Asian/Pacific Islander	59	16	27.1
Hispanic	42	9	21.4
Other/Unknown	20	4	20.0

Chi-square (4)=11.7, p=.02

Table 4: Response Rate By Marital Status

Marital Status	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Single	69	34	49.3
Married	398	144	36.2
Separated	2	2	100.0
Divorced	100	45	45.0
Widowed	85	23	27.1
Unknown	102	37	36.3

Chi-square (5)=14.1, p=.02

Table 5: Response Rate by Facility

Facility	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Facility A	110	26	23.6
Facility B	158	72	45.6
Facility C	88	26	29.6
Facility D	248	84	33.9
Facility E	164	82	50.0

Chi-square (4)=28.0, p<.001

Table 6: Response Rate by Stage

Stage	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
In situ	112	37	33.0
Local	477	173	36.3
Regional	158	72	45.6
Distant	7	2	28.6
Unknown	10	2	20.0

Chi-square (4)=7.2, p=.13

Table 7: Response Rate for 3-Month Survey

	Control Group	Treatment Group	Overall
	N (%)	N (%)	N (%)
Returned 3-Month Survey	130 (90.3)	140 (95.9)	270 (93.1)
Did Not Return 3-Month Survey	14 (9.7)	6 (4.1)	20 (6.9)

Table 8: Response Rate for 12-Month Survey

	Control Group	Treatment Group	Overall
	N (%)	N (%)	N (%)
Returned 12-month Survey	118 (81.9)	134 (91.8)	252 (86.9)
Did Not Return 12-Month Survey	18 (12.5)	8 (5.5)	26 (9.0)
Pending Return	8 (5.6)	4 (2.7)	12 (4.1)

Table 9: Baseline Characteristics: Treatment Group Vs. Control Group

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Facility			.99
Facility A	12 (8.3)	14 (9.6)	
Facility B	37 (25.7)	35 (24.0)	
Facility C	13 (9.0)	13 (9.0)	
Facility D	41 (28.5)	43 (29.5)	
Facility E	41 (28.5)	41 (28.1)	

*Chi-square

Table 10: Baseline Characteristics: Treatment Group Vs. Control Group—Stage at Diagnosis

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Stage at Diagnosis			.82
In situ	15 (10.6)	22 (15.3)	
Local	87 (61.3)	86 (59.7)	
Regional	38 (26.8)	34 (23.6)	
Distant	1 (.7)	1 (.7)	
Unknown	1 (.7)	1 (.7)	

*Chi-square

Table 11: Baseline Characteristics: Treatment Group Vs. Control Group —Age at Enrollment

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Age at Intervention			.10
Under 50 Years	46 (31.9)	34 (23.3)	
50-64 Years	62 (43.1)	81 (55.5)	
65 Plus Years	36 (25.0)	31 (21.2)	

*Chi-square

Table 12: Baseline Characteristics: Treatment Group Vs. Control Group—Education

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Education			.36
8 th Grade or Less	5 (3.6)	4 (2.8)	
9 th -11 th Grade	23 (16.4)	12 (8.3)	
High School Graduate/GED	50 (35.7)	62 (42.8)	
Some College	40 (28.6)	39 (26.9)	
4 Year College Degree	21 (15.0)	27 (18.6)	
Completed Graduate Degree	21 (15.0)	27 (18.6)	

*Chi-square

Table 13: Baseline Characteristics: Treatment Group Vs. Control Group—Employment Status

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Employment Status			.26
Working Full Time	68 (47.6)	56 (38.4)	
Working Part Time	14 (9.8)	21 (14.4)	
Homemaker	8 (5.6)	12 (8.2)	
Student	1 (.7)	0 (0.0)	
Temporary Medical Leave	9 (6.3)	15 (10.3)	
Permanently Disabled	1 (.7)	1 (.7)	
Retired	34 (23.8)	39 (26.7)	
Not Employed, Looking for Work	7 (4.9)	2 (1.4)	

*Chi-square

Table 14: Baseline Characteristics: Treatment Group Vs. Control Group—Language

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Speak Language Other Than English in Home			.71
Yes	19 (13.2)	17 (11.7)	
No	125 (86.8)	128 (88.3)	

*Chi-square

Table 15: Baseline Characteristics: Treatment Group Vs. Control Group—Comfort Speaking English

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Comfort Speaking English			.35
Very Comfortable	17 (89.5)	14 (73.7)	
A Little Comfortable	1 (5.3)	4 (21.1)	
Not At All Comfortable	1 (5.3)	1 (5.3)	

*Chi-square

Table 16: Baseline Characteristics: Treatment Group Vs. Control Group—Living Situation

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Living Situation			.003
Live Alone	22 (15.6)	46 (31.5)	
Live with Partner, Family, Friends	118 (83.7)	97 (66.4)	
Other	1 (.7)	3 (2.1)	

*Chi-square

Table 17: Baseline Characteristics: Treatment Group Vs. Control Group—Marital Status

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Marital Status			.34
Single	11 (7.6)	14 (9.6)	
Married	87 (60.4)	71 (48.6)	
Domestic Partner	13 (9.0)	12 (8.2)	
Divorced	19 (13.2)	32 (21.9)	
Separated	2 (1.4)	2 (1.4)	
Widowed	12 (8.3)	15 (10.3)	

*Chi-square

Table 18: Baseline Characteristics: Treatment Group Vs. Control Group--Close Relatives

Characteristic	Control Group	Treatment Group	P Value*
	N (%)	N (%)	
How many relatives do you have that you feel close to?			.27
None	6 (4.3)	7 (4.9)	
1-2	34 (24.3)	40 (28.0)	
3-5	64 (45.7)	60 (42.0)	
6-9	15 (10.7)	24 (16.8)	
10+	21 (15.0)	12 (8.4)	

*Chi-square

Table 19: Baseline Characteristics: Treatment Group Vs. Control Group—Close Friends

Characteristic	Control Group	Treatment Group	P Value*
	N (%)	N (%)	
How many friends do you have that you feel close to?			.72
None	4 (2.9)	3 (2.1)	
1-2	21 (15.3)	27 (19.0)	
3-5	51 (37.2)	56 (39.4)	
6-9	28 (20.4)	21 (14.8)	
10+	33 (24.1)	35 (24.7)	

*Chi-square

Table 20: Results of Scales at 3 Months—Treatment Group Vs. Control Group

Scale	Control Group	Treatment Group	P Value*
	Mean (SD)	Mean (SD)	
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)--Overall	111.2 (20.2)	110.7 (18.3)	.83
Physical Well-Being	21.7 (5.8)	21.8 (5.9)	.87
Social/Family Well-Being	23.3 (4.5)	22.7 (4.6)	.28
Functional Well-Being	20.2 (5.6)	20.8 (5.3)	.33
Emotional Well-Being	16.6 (3.0)	16.7 (2.9)	.78
Relationship with Doctor	6.7 (1.5)	6.6 (1.6)	.59
Additional Concerns	25.2 (6.2)	25.1 (5.9)	.84
Normed-Based SF-12 Mental Component	51.0 (11.2)	48.1 (11.3)	.03
Normed-Based SF-12 Physical Component	43.4 (7.0)	44.1 (7.4)	.47
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	10.3 (9.2)	10.9 (8.3)	.58
Illness Intrusiveness Scale	33.9 (18.7)	34.2 (17.2)	.92

*t-test

Table 21: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Peer Support Alone

Scale	Control Group Mean (SD)	Treatment Group Mean (SD)	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	107.6 (18.7)	116.7 (15.3)	.04
Physical Well-Being	20.7 (5.6)	23.3 (4.5)	.04
Functional Well-Being	18.9 (5.6)	21.9 (4.9)	.03

*t-test

Table 22: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Group Support Alone

Scale	Control Group Mean (SD)	Treatment Group Mean (SD)	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	114.7 (16.2)	111.0 (20.8)	.68
Physical Well-Being	22.6 (4.7)	20.6 (6.9)	.44
Functional Well-Being	20.2 (5.3)	22.2 (4.4)	.45

*t-test

Table 23: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Both Peer Support and Group Support

Scale	Control Group Mean (SD)	Treatment Group Mean (SD)	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)--Overall	107.5 (23.8)	105.0 (19.8)	.57
Physical Well-Being	20.8 (6.5)	20.8 (6.3)	.99
Functional Well-Being	19.5 (6.3)	19.4 (5.6)	.88

*t-test

Table 24: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Neither Peer Support Nor Group Support

Scale	Control Group Mean (SD)	Treatment Group Mean (SD)	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)--Overall	114.7 (18.7)	112.6 (14.8)	.62
Physical Well-Being	22.3 (5.9)	21.9 (6.1)	.77
Functional Well-Being	21.5 (4.7)	22.1 (4.4)	.60

*t-test



BREAST CANCER PEER SUPPORT PROJECT TWELVE MONTH QUESTIONNAIRE

Please answer the following questions and return the survey in the enclosed prepaid, self-addressed envelope. **All the information you provide in the survey will be kept completely confidential.** Your answers will not be shared with your doctor or employer, become part of your medical record, or affect your Health Plan membership or dues.

1. Overall, how would you describe the care you received at Kaiser Permanente to diagnose and treat your breast cancer?

1 Poor 2 Fair 3 Good 4 Very good 5 Excellent

BREAST CANCER TREATMENT

2. Which of the following treatments have you had or do you plan to have?

	Had in past/ having now 1	Plan to have 2	Do not plan to have 3	Undecided 4
a. Mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Lumpectomy (breast conserving surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Breast reconstruction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Chemotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Tamoxifen (hormonal therapy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Overall, how would you rate your current understanding of breast cancer and its treatment?

1 Poor 2 Fair 3 Good 4 Very good 5 Excellent

DECISION MAKING

- 4. To what extent do you agree with the statement, "You should go along with the doctor's advice even if you disagree with it":**

1 Strongly disagree 2 Disagree 3 Agree 4 Strongly Agree

- 5. To what extent do you agree or disagree with each of the following:**

	Disagree strongly 1	Disagree somewhat 2	Agree somewhat 3	Agree strongly 4
--	---------------------------	---------------------------	------------------------	------------------------

- a. I understand the advantages and disadvantages of each treatment option:

1. Mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Lumpectomy (breast conserving surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Breast Reconstruction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Radiation Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Chemotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Tamoxifen (hormonal therapy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- b. I understand why some treatment options were not available to me
- c. I had enough time to make my treatment decisions
- d. I wish I had had more information about my treatment options
- e. I am satisfied with my treatment decisions
- f. I usually ask my doctor a lot of questions
- g. I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings)
- h. I have difficulty getting the information that I need from my doctor

- 6. How often do you do each of the following?**

	Never 1	Sometimes 2	Often 3	Always 4
--	------------	----------------	------------	-------------

- a. Prepare a list in advance when you visit your doctor
- b. Discuss with your doctor any personal problems that may be related to your illness
- c. Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet
- d. Call your doctor(s) between visits if you have problems

Never 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes 2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often 3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Always 4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. How useful did you find the following breast cancer resources and services?

	Very useful 1	Somewhat useful 2	Not Very useful 3	Not at all useful 4	Did not use 5
a. Kaiser Health Education materials (pamphlets, videos, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Kaiser psychiatrist, psychologist or psychiatric social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Breast Care Coordinator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. American Cancer Society Reach to Recovery Program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Kaiser peer support program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Support group for women with breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Educational and support services for family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Below is a list of statements that other people with your illness have said are important. By checking one box per line, please indicate how true each statement has been for you during the past 7 days.

8. Physical Well-Being

a. I have a lack of energy	<input type="checkbox"/>										
b. I have nausea	<input type="checkbox"/>										
c. Because of my physical condition, I have trouble meeting the needs of my family	<input type="checkbox"/>										
d. I have pain	<input type="checkbox"/>										
e. I am bothered by side effects of treatment	<input type="checkbox"/>										
f. I feel sick	<input type="checkbox"/>										
g. I am forced to spend time in bed	<input type="checkbox"/>										
h. Looking at the above 7 questions, how much would you say your PHYSICAL WELL-BEING affects your quality of life?	(circle one number)										
	0	1	2	3	4	5	6	7	8	9	10
	not at all					very much so					

9. Social/Family Well-Being

- a. I feel distant from my friends
- b. I get emotional support from my family
- c. I get support from my friends and neighbors
- d. My family has accepted my illness
- e. Family communication about my illness is poor
- f. I feel close to my partner (or the person who is my main support)

g1. Have you been sexually active during the past year? No _____ Yes _____

g2. IF YES: I am satisfied with my sex life

h. Looking at the above 7 questions, how much would you say your **SOCIAL/FAMILY WELL-BEING** affects your quality of life?

Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
-----------------	-------------------	---------------	------------------	----------------

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all very much so

10. Relationship with Doctor

- a. I have confidence in my doctor(s)
- b. My doctor is available to answer my questions
- c. Looking at the above 2 questions, how much would you say your **RELATIONSHIP WITH YOUR DOCTOR** affects your quality of life?

Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
-----------------	-------------------	---------------	------------------	----------------

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all very much so

11. Emotional Well-Being

- a. I feel sad
- b. I am proud of how I'm coping with my illness
- c. I am losing the fight against my illness
- d. I feel nervous
- e. I worry about dying
- f. I worry that my condition will get worse
- g. Looking at the above 6 questions, how much would you say your **EMOTIONAL WELL-BEING** affects your quality of life?

Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
-----------------	-------------------	---------------	------------------	----------------

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all very much so

12. Functional Well-Being

- a. I am able to work (include work at home)
 - b. My work (include work in home) is fulfilling
 - c. I am able to enjoy life
 - d. I have accepted my illness
 - e. I am sleeping well
 - f. I am enjoying the things I usually do for fun
 - g. I am content with the quality of my life right now
 - h. Looking at the above 7 questions, how much would you say your **FUNCTIONAL WELL-BEING** affects your quality of life?

(circle one number)

A horizontal scale with numerical labels from 0 to 10. The labels are positioned above the scale line. Below the scale line, there are two additional labels: "not at all" on the left and "very much so" on the right, aligned with the numbers 0 and 10 respectively.

13. Additional Concerns

- a. I have been short of breath
 - b. I am self-conscious about the way I dress
 - c. My arms are swollen or tender
 - d. I feel sexually attractive
 - e. I have been bothered by hair loss
 - f. I worry about the risk of cancer in other family members
 - g. I worry about the effect of stress on my illness
 - h. I am bothered by a change in weight
 - i. I am able to feel like a woman

j) Looking at the above 9 questions, how much would you say your **ADDITIONAL CONCERNS** affects your quality of life?

(circle one number)

A horizontal scale with numerical ticks from 0 to 10. Below the scale, the words "not at all" are positioned under the first two ticks, and "very much so" are positioned under the last two ticks.

Your Health

Excellent **Very Good** **Good** **Fair** **Poor**

14. In general, would you say your health is:

□ □ □ □ □

15. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Check an answer for each activity.)

	<u>HOW LIMITED YOU ARE</u>		
	Not at all	A little	A lot
a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Lifting or carrying groceries	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. Climbing <u>several</u> flights of stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Walking <u>several</u> blocks	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

16. During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health:

- | | | |
|--|--------------------------------|-------------------------------|
| a. Accomplished less than you would like | 1 <input type="checkbox"/> Yes | 2 <input type="checkbox"/> No |
| b. Were limited in the <u>kind</u> of work or other activities | 1 <input type="checkbox"/> Yes | 2 <input type="checkbox"/> No |

17. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious):

- | | | |
|---|--------------------------------|-------------------------------|
| a. Accomplished less than you would like | 1 <input type="checkbox"/> Yes | 2 <input type="checkbox"/> No |
| b. Didn't do work or other activities as carefully as usual | 1 <input type="checkbox"/> Yes | 2 <input type="checkbox"/> No |

18. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- | | | | | |
|---------------------------------------|---|---------------------------------------|--|--------------------------------------|
| 1 <input type="checkbox"/> Not at all | 2 <input type="checkbox"/> A little bit | 3 <input type="checkbox"/> Moderately | 4 <input type="checkbox"/> Quite a bit | 5 <input type="checkbox"/> Extremely |
|---------------------------------------|---|---------------------------------------|--|--------------------------------------|

19. During the past 4 weeks, how much of the time has your physical health or emotional problems limited your social activities (like visiting with friends, relatives, etc.)?

- | | | | | |
|---------------------------------------|---|---------------------------------------|--|--------------------------------------|
| 1 <input type="checkbox"/> Not at all | 2 <input type="checkbox"/> A little bit | 3 <input type="checkbox"/> Moderately | 4 <input type="checkbox"/> Quite a bit | 5 <input type="checkbox"/> Extremely |
|---------------------------------------|---|---------------------------------------|--|--------------------------------------|

20. For EACH of the following questions, please CHECK the answer that comes closest to the way you have been feeling and how things have been with you during the past 4 weeks.

How much of the time during the <u>past 4 weeks</u> :	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
	1	2	3	4	5	6
a. Have you felt calm and peaceful?	<input type="checkbox"/>					
b. Did you have a lot of energy?	<input type="checkbox"/>					
c. Have you felt downhearted & blue?	<input type="checkbox"/>					
d. Have you felt very anxious or nervous?	<input type="checkbox"/>					

21. Check the box for each statement which best describes how often you felt or behaved this way during the past week.

During the <u>past week</u>:	Rarely or None of the Time (Less than 1 day)	Some or a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of Time (3-4 days)	Most or All of the Time (5-7 days)
	0	1	2	3
a. I was bothered by things that usually don't bother me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I did not feel like eating; my appetite was poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I felt that I could not shake off the blues even with help from my family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I felt that I was just as good as other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I had trouble keeping my mind on what I was doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I felt depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I felt that everything I did was an effort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I felt hopeful about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I thought my life had been a failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I felt fearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. My sleep was restless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. I was happy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. I talked less than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. I felt lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. People were unfriendly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. I enjoyed life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. I had crying spells	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. I felt sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. I felt that people disliked me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. I could not get going	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SOCIAL SUPPORT

22. People sometimes look to others for help, friendship, or other types of support. Next are some questions about the support that you have. How often is each of the following kinds of support available to you if you need it?

	None of the time 1	A little of the time 2	Some of the time 3	Most of the time 4	All of the time 5
a. Someone you can count on to listen to you when you need to talk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Someone to give you good advice about a problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Someone to take you to the doctor if you need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Someone to help you understand a problem when you need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Someone to help with daily chores if you are sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Someone to share your most private worries and fears	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Someone to do something fun with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Someone to love you and make you feel wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. How many relatives and friends do you have that you feel close to (feel at ease with, can talk to about private matters, can call on for help). (Check one box for relatives and one box for friends.)

	23a.	23b.
	Relatives	Friends
1 None		
2 1 or 2		
3 3 to 5		
4 6 to 9		
5 10 or more		

24. Is this more or fewer than before your breast cancer diagnosis?

- 1 More relatives/friends than before diagnosis
- 2 Fewer relatives/friends than before diagnosis
- 3 Same number of relative/friends always had

25. How much does your breast cancer and its treatment currently interfere with different aspects of your life? CIRCLE the number that best describes your present life situation.

If an item is not applicable, circle number 1 (one) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered.

	Not Very Much						Very Much	
a. Health	1	2	3	4	5	6	7	
b. Diet (e.g. The things you eat and drink)	1	2	3	4	5	6	7	
c. Work	1	2	3	4	5	6	7	
d. Active recreation (e.g. Dancing, sports)	1	2	3	4	5	6	7	
e. Passive recreation (e.g. Reading, listening to music)	1	2	3	4	5	6	7	
f. Financial situation	1	2	3	4	5	6	7	
g. Relationship with spouse or partner	1	2	3	4	5	6	7	
h. Sex life	1	2	3	4	5	6	7	
i. Family relations	1	2	3	4	5	6	7	
j. Other social relations	1	2	3	4	5	6	7	
k. Self-expression/self-improvement	1	2	3	4	5	6	7	
l. Religious expression	1	2	3	4	5	6	7	
m. Community and civic involvement	1	2	3	4	5	6	7	
n. Planning for the future	1	2	3	4	5	6	7	

Peer Support

26. In the past year, have you talked to a breast cancer survivor about your experience with breast cancer? 1 Yes 2 No, I preferred not to 3 No, I didn't know a survivor

27. IF YES, was this woman: (Please check all that apply.)

- a. A family member
- b. A friend
- c. An acquaintance or co-worker
- d. A Reach to Recovery Volunteer
- e. A Kaiser Peer Support Volunteer
- f. Other (please specify) _____

28. Over the past year, how often did you have contact with a peer support volunteer (either Reach to Recovery or Kaiser)? (Please check the box that applies.)

	Not At all 1	Once or Twice 2	3-5 Times 3	5-10 Times 4	More Than 10 Times 5
a. Telephone calls	<input type="checkbox"/>				
b. In person visit(s)	<input type="checkbox"/>				

29. Was this:

- 1 Less contact than you wanted
- 2 About as much contact as you wanted
- 3 More contact than you wanted

30. If you had a Reach to Recovery or a Kaiser Peer Support Volunteer, how much did she help you in the following areas?

	Very Helpful 1	Somewhat Helpful 2	A little helpful 3	Not at all Helpful 4	Does Not Apply 5
a. Get the information you needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Understand your breast cancer diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Decide what treatment(s) to have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Communicate better with your doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Know what questions to ask your doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Take better care of yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Find out about and use the Kaiser resources better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Deal with job stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Deal with family relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Deal with sexual issues related to breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Anything Else?

Is there anything else you would like to tell us about your breast cancer experience? If so, write your comments here.



BREAST CANCER PEER SUPPORT PROGRAM VOLUNTEER QUESTIONNAIRE

IMPACT OF BREAST CANCER PEER SUPPORT PROGRAM

1. The Breast Cancer Peer Support Program has been valuable for me.

disagree strongly disagree neutral agree agree strongly

In what ways?

2. Volunteering in this program has had a positive effect on my emotional health.

disagree strongly disagree neutral agree agree strongly

In what ways?

3. Volunteering in this program has had a positive effect on important relationships in my life.

disagree strongly disagree neutral agree agree strongly

In what ways?

4. The three-day training was valuable to me.

disagree strongly disagree neutral agree agree strongly

In what ways?

5. The monthly meetings were helpful for me.

disagree strongly disagree neutral agree agree strongly

In what ways?

6. The program helped me to better navigate the Kaiser Permanente system.

disagree strongly disagree neutral agree agree strongly

In what ways?

7. The program helped me better communicate with my doctor.

disagree strongly disagree neutral agree agree strongly

8. The program helped me make decisions about my medical care.

disagree strongly disagree neutral agree agree strongly

9. Keeping a journal was helpful to me.

disagree strongly disagree neutral agree agree strongly

10. Overall, on a scale of 1 to 10, how beneficial to you was your participation in this program?

1=not at all beneficial

10=extremely beneficial

1 2 3 4 5 6 7 8 9 10

VOLUNTEER SUPPORT

11. Overall, do you feel the program supported you enough? Please explain.

OVERALL

12. Overall, on a scale of one to ten, how would you rate this program?

1=not at all valuable

10=extremely valuable

1 2 3 4 5 6 7 8 9 10

13. What could we do to improve the program?

a. The training? _____

b. The monthly meetings? _____

c. Anything else? _____

14. What makes it a positive program? _____

ANYTHING ELSE?

Thank you very much

YOUR BUDDY

Do you think your relationship with _____ helped her to:

1. Understand her breast cancer diagnosis?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

2. Understand her treatment options?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

3. Get a second opinion?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

4. Communicate more effectively with her doctor?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

5. Know what questions to ask her doctor?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

6. Take an active role in her health care?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

7. Find new sources of support?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

8. Find other types of help she needed (e.g., rides, baby-sitting)?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

9. Find out about and use Kaiser Permanente resources?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

10. Deal with job stress?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

11. Deal with family relationships?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

12. Deal with sexual issues related to breast cancer?

1 very helpful 2 somewhat helpful 3 a little helpful 4 not at all helpful 5 does not apply

13. Please discuss any of the above:

ACTIVITIES

How often did you offer the following types of support to your buddy?

14. I shared my experience of breast cancer with my buddy.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

15. I visited with her.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

16. I talked with her on the telephone.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

17. I went to lunch, dinner or coffee with her.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

18. I sent a greeting card to her.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

19. I went for a walk or engaged in another physical activity with her.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

20. I drove her somewhere.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

21. I took her to the doctor.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

22. I went with her to get a prosthesis.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

23a. I did something else with her (please specify): _____.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

23b. I did something else with her (please specify): _____.

1 not at all 2 once or twice 3 3-5 times 4 6-10 times 5 11 or more times

THE MATCH

24. Do you think that you and _____ were a good match?

1 very much so 2 somewhat 3 not really 4 not at all

25. Why or why not?

26. Did you have a lot in common with her?

1 very much so 2 somewhat 3 not really 4 not at all

27. What types of things made it easy to develop a relationship with her?

28. What types of things made it difficult to develop a relationship with her?

29. Reflecting on your experience with this buddy, are there other things we need to take into consideration when we match buddies with volunteers?

30. Overall, how useful do you think this program was for your buddy?

1=not at all useful

10=extremely useful

1 2 3 4 5 6 7 8 9 10

31. Anything else?
